

# siyam'kela

measuring  
related  
hiv/aids  
stigma

Promising practice of stigma-mitigation  
efforts from across South Africa:

Reflections from

- faith-based organisations
- the workplace and
- people living with HIV/AIDS who interact with the media





## Siyam'kela

*Siyam'kela [SI-YUH-MU-GE-LAR] is an African word from the Nguni language. Translated it means "We Are Accepting" expressing a collective embracing, understanding and acceptance of a challenge at a particular time. The word has thus been interpreted as "Together We Stand" for this project.*

*The Project has been designed to explore HIV-related stigma, an aspect of the HIV/AIDS epidemic, which is having a profoundly negative effect on the response to people living with, and or affected by HIV/AIDS. Within the context of the Project, Siyam'kela denotes a collective approach in working towards reducing HIV/AIDS related stigma and discrimination.*

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## *Promising practice of stigma-mitigation efforts from across South Africa:*

*Reflections from*

- *faith-based organisations*
- *the workplace and*
- *people living with HIV/AIDS who interact with  
the media*

March 2004

*A joint project of the:*

- POLICY Project, South Africa;
- Centre for the Study of AIDS, University of Pretoria;
- United States Agency for International Development (USAID); and
- Chief Directorate: HIV/AIDS & TB, Department of Health

*Supported by:*

- Representatives from the Siyam'kela Reference Groups

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measuring HIV/AIDS  
related stigma...





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## 1. Background of Siyam'kela study

The Siyam'kela Project is a joint endeavour of the POLICY Project, the Centre for the Study of AIDS at the University of Pretoria, the United States Agency for International Development (USAID), and the Chief Directorate: HIV, AIDS and TB, National Department of Health. *Siyam'kela* is an African word meaning 'we are accepting', expressing a collective embracing. The project has interpreted the word as 'together we stand', to symbolise unity in challenging HIV/AIDS stigma.

Stigma, 'a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons'<sup>1</sup>, can be **felt** (internal stigma), leading to an unwillingness to seek help and access resources, or **enacted** (external stigma), leading to discrimination on the basis of HIV status or association with someone who is living with HIV.

Because stigma has an impact on prevention and care it is important to address it directly. However stigma-mitigation practice has not been well informed by theory and research. An urgent need was identified for indicators of stigma, which can be used to develop interventions and measure their success.

The Siyam'kela Project thus aims to pave the way for a stigma-mitigation process by developing **well-researched indicators** of HIV/AIDS stigma and discrimination. The Project has focused on three key areas essential to South Africa's response to HIV/AIDS:

- faith-based organisations and communities as important sources of support to people living with HIV/AIDS (PLHAs)
- government departments as workplaces committed to dealing with stigma through good policy and practice
- the relationship between PLHAs and the media as an example of how empowered individuals can impact positively on perceptions and attitudes towards HIV/AIDS.

A comprehensive literature review, two consultative workshops and the establishment of reference groups in the focus areas of the project ensured that a diverse range of opinions and experiences were reflected. The use of an independent research organisation, Insideout, for the fieldwork, also brought in a fresh perspective.

The Project consists of **six aspects**:

- a literature review to provide a theoretical understanding of stigma
- a qualitative exploration of **stigma experiences and perspectives** through focus group discussions and key informant interviews across South Africa
- the development of **indicators of internal and external stigma** through this fieldwork and in consultation with experts in the field
- a **media scan** to contextualise and locate the fieldwork in a particular time and place
- the documentation of '**promising practices**' which mitigate HIV/AIDS stigma
- the development of **guidelines** to assist those who wish to develop interventions to impact positively on HIV/AIDS stigma

This report focuses on the fifth aspect of this project, namely the documentation of promising practices to mitigate HIV/AIDS stigma.

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<sup>1</sup> Canadian HIV/AIDS Legal Network. (1998). *HIV/AIDS and Discrimination: A Discussion Paper*. Ottawa, Canadian HIV/AIDS Legal Network and the Canadian AIDS Society.



## 2. Introduction

Promising **practices** from the three focus areas have a crucial role to play in offering leadership, vision, direction and inspiration in stigma mitigation. Faith-based organisations are important institutions in shaping values and attitudes to vulnerable people in society as well as developing appropriate and compassionate responses to social challenges. Government departments, both as employers of large numbers of South Africans and as providers of services to the population at large, are able to model exemplary policies and programmes around HIV/AIDS stigma. PLHAs who are able to interact with sophistication and confidence with a range of media are inspiring not only to other PLHAs but they also challenge notions of PLHAs as victims or undesirables and confront media organisations and practitioners on their own assumptions, values and practices.

The promising practices which follow cover two broad areas:

1. Policy-related interventions which impact positively on HIV/AIDS stigma in the form of:
  - the public service policy framework to guide HIV/AIDS interventions in government departments
  - exploration of texts and leadership in faith-based organisations
  - guidelines for media practitioners and PLHAs
2. Programmatic interventions across all three areas which include:
  - prevention
  - treatment
  - care

Cutting across these two broad areas are some key themes. Work to challenge and address stigma must be ongoing, reflective and integrated into all activities. It should also involve partnerships with all stakeholders, PLHAs at every point and all levels of staff in an organisation.

Each set of practices contextualises the examples chosen, highlights specific activities around stigma mitigation and documents lessons learned. This is followed by an integration of the key findings. As you read through the promising practices, which we have selected, we hope you will be able to find ideas to stimulate and inspire you in your professional and personal life.

## 3. Faith-based organisations

Interviews were conducted with a range of people in the faith-based sector, including religious leaders, members of faith groups and PLHAs. This report summarises promising practices, which emerged in each of the interviews.

Three of the interviews – with the group Positive Muslims, with Rev Nobula of the Church of Christ and with Rev Jones of the Anglican Church – highlighted the importance of **introducing a new language** to talk about HIV/AIDS in a way which reduces stigma and allows for PLHAs to feel accepted and integrated into the faith community. This enables mainstreaming the concerns of PLHAs. The respondents said that an important step in developing such language is to use **traditional religious texts** – such as the Bible and the Qur'an – in a way which encourages acceptance and care for PLHAs. Ideas of HIV/AIDS as denoting sinfulness needed to be challenged and replaced by the idea of a compassionate response to the pandemic.

Another key element in the response of faith-based organisations was to **involve PLHAs** at every level of the faith groups' HIV/AIDS programmes. This strategy was mentioned by all three Christian leaders interviewed. Such a response not only utilises the skills and knowledge of PLHAs, but also serves to make PLHAs more visible and hence help to reduce HIV/AIDS-related stigma in faith communities.





The notion of **partnership** between faith groups received support from those interviewed. This enables faith groups to learn from each other and to support each other in programmes to challenge HIV/AIDS stigma.

Finally, Rev Jones of the Anglican Church, Rev Xapile of the Uniting Presbyterian Church and the group Positive Muslims said that it was crucial to address the issue of sexuality and religion, despite traditional religious taboos on speaking about it. Faith leaders said that given that HIV/AIDS is most often sexually transmitted, no adequate response can ignore the sexual dimension.

### 3.1 'HIV/AIDS is not a punishment from God'

#### 3.1.1 Background

The Church of the Province of Southern Africa (Anglican Church) was chosen as a faith-based organisation for this study for three reasons: it has a highly visible role in South Africa in terms of HIV/AIDS, it has assumed a national advocacy role in HIV/AIDS, and it has been allocated the largest amount of funding to an FBO by DFID to implement an HIV/AIDS-related stigma reduction programme. The Anglican Church has taken a bold stand in attempting to reduce stigma by advocating nationally that "HIV/AIDS is not a punishment from God." The Church has clearly come to have an important influence on other faith-based organisations.

The Anglican Church has received funding of R45 million from the UK Department for International Development (DFID) over a 3-year period to fund a range of HIV/AIDS programmes throughout all its Southern African diocese. The programmes are to focus on wellness, home-based care, orphans and vulnerable children, youth and women. In terms of the grant, every programme is to include a component, which serves to reduce HIV/AIDS stigma.

The Anglican Church's interventions have been at two levels: theological reflection and practice. Theological reflection about HIV/AIDS has involved academic study about the implications of the HIV/AIDS pandemic for the church, conducting training with clergy and reflecting about the meaning of responsible sexuality. Practical interventions have involved home-based care, counselling, education, orphan care, training of caregivers, challenging gender inequality and wellness management. The Anglican leadership has also played a prophetic role in challenging government and giving voice to the concerns of the poor and voiceless.

Reverend Colin Jones, the director of the HIV/AIDS programme for the Church of the Province of Southern Africa, was interviewed about the Anglican programme. Rev Jones is 53 years old and was first drawn into HIV/AIDS work in 1988, when he was dean of St George's Cathedral in Cape Town, and became involved in hospice care.

He said that the Anglican Church had begun to respond to the HIV/AIDS pandemic more effectively after a meeting of all the Anglican Churches in Africa in Boksburg in 2001 to address the HIV/AIDS pandemic. At this meeting the importance of the church addressing stigma was explicitly acknowledged. The Boksburg conference produced a vision statement for the Anglican Church regarding HIV/AIDS. It drew up a strategic plan for HIV/AIDS ministry and outlined six key areas of concern, including leadership, care, prevention, counselling, pastoral care, and death and dying.

Rev Jones said that the Boksburg conference had been crucial in recognising that:

*"Religion can play a very negative role in terms of promoting stigma. Issues of sex are often defined as issues of sin because within the African context HIV/AIDS is mostly linked to sexual activity."*



### 3.1.2 Strategies to reduce stigma

#### Adopting an inclusive approach

HIV/AIDS is often depicted as a disease affecting the poor, black, prisoners, women, homosexuals, sex workers or promiscuous heterosexuals. This perpetuates the idea that people who do not belong to these categories are not susceptible to infection, which, it turn may encourage risk behaviour to these groups. This “othering” perception subsequently leads to stigmatisation of the groups perceived as risky. Rev Jones argued that it was an important step in stigma reduction to see the whole body of the church as having HIV/AIDS. In this way HIV/AIDS stopped becoming the problem of just individual PLHAs, and became the responsibility of the entire religious community. In his words, ‘all are affected by AIDS, even if all are not infected’. This approach creates inclusiveness and breaks down stigma.

#### Rethinking sexuality

Rev Jones said an important promising practice for stigma mitigation was for faith organisations to see:

*“Responsible sexuality as a gift from God, something wonderful, not negative. Sex does not equate to sin. The idea that there is something wrong about sex, we believe that tradition is not a healthy one. I think a challenge is to know how to teach about sex without emphasising sin.”*

Rev Jones suggested that if faith organisations could promote a view of sexuality as healthy and good, it would assist their members to be less judgemental of PLHAs who had contracted the virus sexually. This would in turn reduce HIV/AIDS stigma.

#### Addressing judgemental attitudes

Another important promising practice, which he identified, was developing an alternative to the model of a vindictive and judging God who used HIV/AIDS as a punishment for human sin. Rev Jones said that the idea of a compassionate God was to be preferred, as it reduced the judgementalism of members of faith groups regarding HIV/AIDS. In this way, stigma was also mitigated.

The Church often interpreted the Bible in a narrow way, and this had to change:

*“The Bible is often read and interpreted in such a way I think to encourage a stigmatising attitude and practice, and to marginalise people. But we believe that the real story of the Bible is about a God who is inclusive, not exclusive. In the context of stigmatisation what we want to do is to try to reclaim those stories in the Bible that talk of inclusion ... God seeks to redeem creation and humanity, not to condemn it.”*

He added that:

*“The Church needs to reclaim the teachings of Christ – to use the Bible as a source of reconciliation rather than destruction.”*

#### Visibly involving PLHAs

Rev Jones believed that it was crucial for faith organisations to visibly involve PLHAs at every level of their response to the pandemic. It was also important for faith leaders to publicly identify with PLHAs. Such involvement not only helped ensure that faith organisations had an appropriate response to the pandemic, but also reduced stigma among members.

Rev Jones said that some faith leaders in the Anglican Church were themselves HIV positive:

*“There are indeed clergy living with HIV/AIDS. And there are probably political leaders living with HIV/AIDS. What we need to do is change the climate so that it is possible for people in these leadership positions to come out and identify themselves with people living with HIV/AIDS. That will make a tremendous difference.”*



He argued that the visibility of faith leaders living with HIV/AIDS went a considerable way to destigmatising the disease.

### Using the church as a resource

According to Rev Jones, the Anglican Church, even in rural areas, had many resources which could be utilised for HIV/AIDS work:

*"Even in the remotest villages there is access to a church ... we can use these facilities for AIDS work, educating people to spread the message. We can also use our resources in the community, for instance, caring for people living with HIV/AIDS by providing home-based care support, and by providing spiritual and emotional support to people. Orphan children are another important area."*

### Working in partnership

Another important stigma-mitigation practice, which he identified, was for faith organisations to work together in partnership to address the HIV/AIDS pandemic. He said that this was already happening between the mainstream Christian denominations. However, partnerships needed to be extended to include smaller and traditional African churches, as well as groups representing other faiths.

#### 3.1.3 Lessons learned

Rev Jones reflected that his experience of working in the HIV/AIDS field had led him to see that:

- talking about HIV/AIDS in terms of sin is not helpful as it puts PLHAs into a situation of feeling judged
- in HIV/AIDS it is important to engage in both practical care, as well as reflection at the intellectual and theological levels on the meaning of the disease
- it is important to speak the message of responsible morality regarding sexual behaviour
- it is necessary to challenge gender practice in the Church that disempowers women in order to show people what we want to move towards building strong women who make choices for themselves.

## 3.2 Involving people living with HIV/AIDS

### 3.2.1 Background

Reverend Dr Spiwo Xapile is the 46 year-old pastor of the JL Zwane Memorial Uniting Presbyterian Church in Guguletu, Cape Town, and is also involved in the JL Zwane Response to HIV/AIDS. Rev Dr Xapile was first drawn into working in the HIV/AIDS field in 1996, when he realised that some of the church members were HIV positive. He subsequently sought training to deal with the HIV/AIDS issues he had confronted through several bodies, including the South African Council of Churches, the All Africa Council of Churches and the World Council of Churches. Today, in addition to his church commitments, Rev Dr Xapile is also involved in teaching courses for the Postgraduate Diploma in the Management of HIV/AIDS in the World of Work at Stellenbosch University.

The Guguletu church has a close working relationship with a group of Christians in Minnesota, USA, who have been generous in assisting with funding its HIV/AIDS work. Rev Dr Xapile has taken a particularly noteworthy stand on the full and public inclusion of PLHAs in the church. Rev Dr Xapile said the inclusion of PLHAs was important because they were also part of the body of the church:

*"... and if a certain part of the body is not alright the whole body is affected. So we have to look to taking care of that part of the body. We cannot just forget about it, ignore it."*



He said that the HIV/AIDS programme of the church had two main aims: to reduce stigma, and to provide support to members living with HIV/AIDS.

### 3.2.2 Strategies to reduce stigma

#### Studying the texts

Rev Dr Xapile said that the church's approach to PLHAs needed to be based on a long process of reflection, which started with finding a sound theology for approaching HIV/AIDS. He spoke about the need for churches to return to a close study of the Christian gospel in order to mitigate HIV/AIDS stigma:

*"The Church will wrestle with theology first, that's the difficult thing. The Church always wants a scriptural message to say, this is about this, what is our response theologically. It then takes an argument and lots of discussion before [the church members] decide to do something."*

He said that the Gospels were particularly challenging to those who stigmatised people living with HIV/AIDS:

*"I think if you read Matthew 25, you will find it very hard [to engage in condemnation] of people who are HIV positive ... I think [in that passage] if there's any judgement, it is not on the people that are infected and affected by HIV/AIDS, an element of judgement is towards how the church respond to people that are affected by HIV/AIDS."*

#### Bringing together diverse opinions

Rev Dr Xapile identified the need to reconcile those in the church who had strongly opposing views of the HIV/AIDS pandemic. He said an important role was played by what he described as 'the ministry of reconciliation' in the church in alleviating stigma. He said that in practice this meant bringing together in a religious service PLHAs and members who engaged in stigmatisation, in order to build new and healed relationships between them.

#### Challenging responsibility

In his view, stigma reduction could also occur through making members of faith organisations aware that the HIV/AIDS pandemic was:

*"The responsibility of everyone; people living with HIV/AIDS, those that are affected and those that are not affected by HIV/AIDS."*

The extensive involvement of the faith group in all aspects of HIV/AIDS derived, he said, from an understanding of the faith community as:

*"... the body of Christ, which means that there is the whole question of us belonging to one another and if one suffers, everyone suffers. There is a call to really carry each other's burdens and be involved."*

#### Going beyond support groups

Rev Dr Xapile pointed out that the involvement of his faith group extended beyond the integral inclusion of PLHAs to include a programme for children orphaned by AIDS, emergency food relief for the destitute, condom distribution, and an education and awareness programme. The faith group also provided a skills-training programme for women in basic homecare and training for health care workers in HIV/AIDS.



## Mainstreaming AIDS and sexuality education in church services

An innovative strategy used by Rev Dr Xapile was to incorporate in every church service a 15-minute educational session on HIV/AIDS and sexuality. PLHAs were involved in conducting these educational sessions. Rev Xapile said of the educational sessions:

*"The members of the congregation come to me and say that helps a lot because it serves as an introduction to talking about sexuality and AIDS. They would say that it's much easier to start a conversation at home with our children by saying, you've heard that in church."*

Mentioning HIV/AIDS and sexuality in a religious context appears to legitimise talking about it in a domestic context as well. This enables families to communicate more openly about HIV/AIDS, and to hence reduce its stigma.

### 3.2.3 Lessons learned

In reflecting on his HIV/AIDS work, Rev Dr Xapile said that the following lessons had emerged:

- it was crucial in this type of work to have a clear and pure motivation; motivation was crucial to enable one to cope with the discouragement that working in HIV/AIDS also brought
- motivation needed to be defined theologically as well as practically
- one should be open to new lessons, even shocking ones
- it was important to integrate religious language with secular HIV/AIDS language
- involving PLHAs in the church greatly changes the life of the faith community in unexpected ways
- one should learn to listen to the suggestions of faith group members regarding how to respond to HIV/AIDS.

## 3.3 Building the capacity of faith leaders

### 3.3.1 Background

Reverend Martin Nobula is a 38-year-old pastor of the local Church of Christ in Southern Africa in New Crossroads, near Cape Town. He has undergone various pastoral training courses, as well as HIV/AIDS counselling and pastoral training through the Western Cape offices of the Family and Marriage Society of South Africa (FAMSA). He got involved in working in HIV/AIDS after attending a meeting in March 2000 of faith leaders, which was addressed by Dr Nono Simelela of the National Department of Health, who challenged the group attending the meeting to respond to the HIV/AIDS pandemic.

In response, Rev Nobula identified the need for the capacity building of faith leaders of the Church of Christ in Southern Africa in the Western Cape, in order to enable them to respond to the pandemic in a non-stigmatising way. He then approached FAMSA for help. FAMSA agreed to develop a training programme in HIV/AIDS for faith leaders and the church workers. The training programme which aim at enabling trainees to listen and relate to others in a non-judgemental and empathic way, covers general HIV/AIDS and a pastoral component which is provided by a faith leaders, integrated into a 5-day programme. Rev Nobula has continued to be part of the training process, as well as developing the Ikwezi Community Service Project based at New Crossroads, whose activities are outlined below.





### 3.3.2 Activities to reduce stigma

#### Alternative textual analysis

Rev Nobula pointed out the importance of providing faith leaders with an alternate, non-stigmatising perspective on HIV/AIDS. Such a perspective, he said, could be derived to a significant extent from texts from key religious writings which supported and encouraged a caring response to PLHAs in religious groups. Rev Nobula suggested that such texts allowed leaders and members of faith groups to engage in a more compassionate response to members who were HIV positive, as they taught a different perspective to the stigmatising discourse prevalent in many faith groups:

*"What is mostly taught is love, and that God loves us all. We are children of God, regardless of who we are and what we are. So that is the most important thing that is being taught here – to destigmatise and to love one another."*

Rev Nobula added that to enable members of faith groups to tackle AIDS stigma:

*"... there is no other method you can use more than teaching people to be loving, to be humble to one another and to be caring ... to be able to live together and to care."*

The training course for faith leaders drew heavily on a pastoral document provided by faith leaders involved in the training, describing a range of interpretations of key Biblical passages, which were seen as useful in the HIV/AIDS pandemic. Some of these texts exhorted Christians to follow God's example in being loving and forgiving of all. As Rev Nobula pointed out, the passages had the power to counter HIV/AIDS stigma by asking Christians to extend the same love to all, including PLHAs, through following God's example:

*"God's love is extended to all people ... God's grace and forgiveness is greater than our sin."*

#### Challenging internal stigma

In addition, the Biblical passages in the FAMSA document also had the potential to challenge the internalised stigma of PLHAs who are members of faith organisations:

*"In the midst of the challenges of HIV/AIDS, we can be assured that God still loves us ... God promises to bring good results out of difficult situations ... HIV affects the body but hope is found in the soul."*

Rev Nobula argued that such Biblical passages had enormous power to reduce HIV/AIDS stigma. The document he quoted from had, he said, been translated into the Xhosa language, to enable leaders and members of traditional African churches to also use these ideas in their ministry.

The pastoral document was also widely used by PLHAs in Rev Nobula's church, in order to give comfort and reassurance. In this respect the document had the potential to challenge the internalised stigma of PLHAs.

#### Strategically involving PLHAs

Another key component of the FAMSA training course for faith leaders and opinion leaders was the use of PLHAs in the training programme. Rev Nobula said that their involvement challenged stereotyped ideas which leaders had about PLHAs.

Rev Nobula mentioned that contact with PLHAs who were open about their status was crucial to reducing stigma in faith organisations, and urged that if no PLHA who was a member of the faith organisation was willing to be open about their status, a PLHA 'from outside needed to be brought in' to talk about HIV/AIDS.



The church had regular HIV/AIDS awareness days, where PLHAs spoke to members of the church in interactive sessions. Rev Nobula felt that these sessions were very powerful educational tools.

### Awareness raising

Rev Nobula said that his church was also involved in educating its members about HIV/AIDS in a range of ways, including facts about HIV/AIDS transmission and living positively. He felt that deciding what faith organisations should say about the prevention of HIV transmission was difficult, given the opposition to condom use in many faith contexts on the grounds that it encouraged immoral sexual behaviour. He suggested that this should not discourage faith organisations from trying to provide answers. One possible response to this difficulty was to provide a very broad message of awareness and to stay free from infection.

### Challenging irrational fears

In Rev Nobula's view, another important aspect of working in faith organisations was to provide basic information to members about HIV/AIDS and its transmission, in order to counter irrational fears of infection through social contact with PLHAs:

*"When you reject a person living with AIDS, it is usually [the fear that] the person is going to infect us. Like when an infected person makes food for us, that he or she will infect us."*

By providing basic factual information, faith organisations had the potential to reduce HIV/AIDS stigma.

### Running support groups

Through the Ikwezi Community Service Project, Rev Nobula also ran three support programmes, including a support group for PLHA women and men. A member of the group who was interviewed said that she had experienced stigmatisation in a faith group of which she had previously been a member because of her HIV positive status, which had led her and her husband to leave that group. However, her experience in Rev Nobula's group had been a very different one:

*"We told [the support group members] about our status and they welcomed us, they told us they will not judge us as God himself would not want them to do that to us. Some pastors even told us that God still loves us and He will always be on our side."*

This had challenged her own internalised stigma, and as she elaborated further:

*"People ask how I manage to live happily, and I always say acceptance is the most important thing ... Treatment without acceptance will not help as you will only feel depressed."*

#### 3.3.3 Lessons learned

In doing this work Rev Nobula reflected that he had learned the following lessons:

- the more that one talked about HIV/AIDS, the greater the level of understanding of the faith group; however, it was also important to expect lots of resistance
- there was a need in doing this type of work to continually inform oneself about the most up-to-date information
- in order to work with PLHAs effectively it was important to have a healthy dose of humility
- at all times it was important to act out of love, and not to judge
- working with those dying of AIDS-related illnesses was a very emotionally draining experience, for which one needed to have good support.



### 3.4 Reaching out to the community

#### 3.4.1 Background

Positive Muslims is a Cape Town group, which was started in June 2000 out of the need in the Muslim community for a strong advocacy role in the HIV/AIDS pandemic. The group is involved in raising awareness of HIV/AIDS in the Western Cape Muslim faith community and in providing support to Muslims living with HIV/AIDS. Its three main focus areas are: firstly, providing support and counselling; secondly, providing education and raising awareness; and thirdly, conducting research in the Muslim community about the extent of HIV infection, as well as developing a new Muslim theology for HIV/AIDS.

Positive Muslims has four full-time staff, six executive committee members and 40 volunteers.

#### 3.4.2 Strategies to reduce stigma

##### **Developing a theology of compassion**

Ms Farahneez Hassiem, the Education and Awareness officer said that Positive Muslims had tried to develop a comprehensive theology of compassion:

*"In the Muslim community the study of compassion addresses the discrimination and prejudice that the Muslim person living with HIV faces in every aspect of their daily lives, it also addresses the issue of justice ... we cannot be judgemental towards people who have been diagnosed with HIV/AIDS."*

Through producing a comprehensive theology, it was hoped that a less condemnatory approach to HIV/AIDS amongst Muslims would be facilitated, in order to reduce HIV/AIDS stigma.

##### **Reviewing texts**

The group member said that it was important to read the Muslim holy writings, the Qur'an, in new and innovative ways:

*"Our reading can never limit the Qur'an. The Qur'an is miraculous because of its ability to transform the reader. It is not a passive text but has an inexhaustible number of readings, depending on the reader's context. On the contrary, depending on the reader's God consciousness, the text will surface meanings hitherto hidden."*

By reading the Qur'an carefully it was possible to use it to challenge HIV/AIDS stigma and to argue for a more accepting response:

*"It is only when we are able to establish the right balance between *jalah* (a strong sense of justice) and *jamal* (an unlimited compassion), that we will be able to perhaps display what Allah intended of us - *kamal* (perfection)."*

##### **Offering leadership training**

Another important tool in stigma mitigation which Positive Muslims utilised was to provide leadership training through educational workshops regarding HIV/AIDS for religious leaders such as imams. Such workshops involved the provision of basic facts about the disease and also tried to challenge myths about the pandemic. According to Ms Hassiem, the workshops had had tangible results: imams had begun to publicly acknowledge HIV/AIDS and to express a more compassionate response to it.

##### **Addressing sexuality**

Positive Muslims saw sexuality as an important area to address, despite the traditional taboos in the faith community on talking about it:





*"We are addressing issues such as faithfulness in the sense of being honest about your [sexual] activity, take an ownership of your sexual activity ... start sitting down and taking a decision how you are going to conduct your life and what kind of behaviour you choose."*

### Running outreach programmes

The group also provided an extensive outreach programme to Muslim youth, whom it tried to involve in a variety of social activities, but with an underlying HIV/AIDS message. Community outreach also took the form of running support groups for Muslims living with HIV/AIDS, and staffing a 24-hour counselling helpline, which provided telephone counselling regarding HIV/AIDS. Ms Hassiem said that the service was well utilised because of the strong guarantee of anonymity.

### 3.4.3 Lessons learned

Ms Hassiem reflected that the following lessons had been learned from the group's experiences of the previous three years:

- the group provides a very important space for PLHAs to be not only HIV positive but also Muslim
- strategies need to be adapted to meet the needs of particular groups, e.g. youth, faith leaders
- in dealing with HIV/AIDS practice needs to be continually referred back to the Qur'an
- the theology of compassion is central to HIV/AIDS work.

### 3.5 Key findings

A number of most promising practices in stigma mitigation emerged from the interviews with representatives of faith-based organisations, including leaders and opinion leaders. The most important of these most promising practices were the following:

- providing resources in the form of religious texts which would encourage a more compassionate response to PLHAs, both within and outside of faith-based organisations. Members of both Christian and Muslim groups identified this as a most promising practice
- allied with this was the development of a theology which saw God as loving and affirming, rather than as a judgemental and punishing figure
- providing basic information about HIV/AIDS transmission to members of faith groups, especially where such knowledge is seriously lacking. In many cases, basic information also needs to be provided to faith leaders in order to mitigate stigma
- promoting a view of sexuality in faith organisations as healthy and good, rather than as sinful and negative. Since sexuality is closely associated with HIV/AIDS, a more positive view of sexuality will promote a more enlightened view of HIV/AIDS. A context that promotes open and frank discussion about sexuality is equally important
- encouraging a 'ministry of reconciliation' between PLHAs in faith groups and members who engaged in stigmatisation, in order to build new and healed relationships
- ensuring that PLHAs within faith-based organisations have a safe space, and are hence able to disclose their HIV status to other members of the faith group without fearing stigmatisation or rejection
- encouraging PLHAs to participate fully in the activities of faith-based organisations, as well as promoting PLHAs to positions of leadership in such organisations
- encouraging leadership living with HIV/AIDS to disclose their HIV status to other members
- developing partnerships between faith-based organisations to address the HIV/AIDS pandemic in various ways, including stigma reduction.



## 4. The workplace

Interviews were conducted with a range of representatives of government workplaces.

The co-ordinator of the Interdepartmental Committee on HIV/AIDS (IDC), Mr Knigge, and the Employee Assistant Programme (EAP) Professional of Statistics South Africa, Ms Theo, both spoke about the importance of utilising the Greater Involvement of People Living with HIV/AIDS (GIPA) Principle in the workplace. This principle needs to be implemented with care, they said. However, it does have the potential to ensure a wide range of benefits, including offering a visible role model to other PLHAs, informing the development of HIV/AIDS programmes, and providing the opportunity for informal counselling in the workplace to PLHAs.

Representatives of the workplace who were interviewed emphasised that the mitigation of HIV/AIDS stigma is a long-term process which is never complete. As such, it cannot be confined to a single campaign or undertaking, but needs to be **integrated into a range of ongoing activities in the workplace.**

The importance of a progressive HIV/AIDS workplace programme for stigma mitigation was highlighted by the South African Police Services (SAPS). Crucial components in the SAPS programme's success are the support shown for it at all levels of management, and the provision of a cascading programme of information and counselling.

Promising practices, which emerged from interviews with workplace representatives, are described in more detail below.

### 4.1 Creating an environment of collaboration and learning

#### 4.1.1 Background

The national Interdepartmental Committee on HIV/AIDS (IDC) was set up by the South African government in 1998 in order to provide an organ to assist government departments with capacity building regarding HIV/AIDS policies. The IDC has a secretariat, which is financed and supported by the Department of Health.

The IDC co-ordinator, Niko Knigge, was interviewed regarding promising practices for HIV/AIDS stigma mitigation. Mr Knigge attributed part of the success of the IDC to the fact that it had democratically elected leadership and an elected chairperson. This ensured accountability and a sense of ownership of the process.

The informal forum provided for government departments to discuss HIV/AIDS issues provided an important opportunity for networking and the sharing of expertise, according to Mr Knigge:

*"We will be saying, OK, you want an impact assessment, go to this department, they have done it. Or you need a trainer for this, we can recommend Mr X. So each department can learn from what the next has done. They don't have to find it all out for themselves."*

Although it was hard to measure the impact of the IDC on government departments, he said, generally departments which had participated in the IDC and attended trainings had more developed HIV/AIDS workplace policies in place and seemed to have lower levels of stigma in the workplace.



#### 4.1.2 Activities to reduce stigma

##### Challenging attitudes

Mr Knigge commented that the IDC saw it as important that government departments continually challenge attitudes in the workplace regarding HIV/AIDS. He said that horizontal interventions were more important in this regard than vertical interventions. This meant challenging attitudes at all levels of the workforce, rather than just utilising top-down messages from management to lower-level employees.

Mr Knigge added that continually challenging attitudes had a powerful effect in the long term as stigma was reduced, and this served to improve the 'quality of life' of those employees who were HIV positive.

##### Promoting non-discriminatory values to reduce stigma

Non-discriminatory values are an underlying principle of HIV/AIDS programmes of national government departments and of the work facilitated by the IDC. These values are based on the HIV/AIDS and STD Strategic Plan for South Africa 2000-2005 and the Public Service regulations on HIV/AIDS<sup>2</sup>.

Whilst stigma receives some direct attention in IDC communications, Mr Knigge suggests that a more powerful way to confront stigma is through ongoing promotion of values of acceptance. At IDC level such communication is disseminated by means of general communication, assistance with planning, policy review, capacity building and organising of interdepartmental campaigns.

*"It's not enough to have these messages once a year, on AIDS Day or whatever, because the impact will not be enough. It's better to try and think of ways, of how you can get messages about AIDS across in everyday communication. ... it's about using every opportunity to slip in a message about HIV/AIDS, use every opportunity."*

The effect of ongoing messages, he said, was a subtle one, but they nevertheless led to gradual but pervasive change in organisational culture, hence in the long term reducing stigma.

##### Challenging messages on gender

Mr Knigge emphasised parallels between addressing HIV related discrimination and gender transformation, and to challenge sexist attitudes and practices in the workplace:

*"As with HIV, unhelpful gender attitudes are deeply anchored and need to be challenged continuously. Gender must be highlighted, because it's behind the spread [of HIV/AIDS]."*

##### Addressing ethical concerns

While there have been some rare instances of breach of confidentiality, to date the IDC secretariat has not been confronted with instances of overt stigma or discrimination at the workplace. The breaches of confidentiality were handled by means of counselling the official involved and organising education for the affected business units.

##### Participating in research

The IDC is a key partner in the Siyam'kela Project and has assisted in the development of indicators of stigma. This was done through facilitating access to national government departments and by giving ongoing input as part of reference groups advising the project. Continuous engagement with the Siyam'kela Project sensitised and enabled participating departmental HIV/AIDS focal persons to understand HIV/AIDS stigma and the manifestations of stigma in the workplace. Furthermore their participation in

<sup>2</sup> Department of Public Service and Administration, (2001), Public Service Regulations. Access at <http://www.gcis.gov.za> and <http://www.dpsa.gov.za>



focus-group discussions and key-informant interviews facilitated discourse around stigma. This self-awareness and self-reflection process has subsequently put stigma on the agenda of departmental HIV/AIDS programming.

### **Greater Involvement of People Living with HIV/AIDS (GIPA)<sup>3</sup>**

The IDC actively promotes the involvement of persons living openly with HIV and/or AIDS in departmental HIV/AIDS programmes. Mr Knigge referred to the principle of Greater Involvement of People Living with HIV/AIDS (GIPA) as a powerful strategy to address stigma head on. In partnership with the United Nations Development Programme, the IDC has applied the GIPA workplace model to government departments: Six persons living openly with HIV were recruited, trained and placed as HIV/AIDS co-ordinators in selected departments. This strategy was replicated by other departments with their own budgets but with technical assistance from the IDC:

*"It sends a strong message of acceptance to other employees. They get to see this strong person who is [HIV] positive. It also gives the opportunity for informal counselling in the workplace of the PLHA who is openly talking to other employees. And then also, it normalises HIV/AIDS ... and I suspect it creates a momentum, which makes it easier for other people living with HIV/AIDS to disclose and this reduces stigma and discrimination."*

Mr Knigge suggested that the GIPA principle had the potential to make a major contribution to reducing HIV/AIDS stigma.

### **A continual process**

Mr Knigge suggested that the mitigation of stigma was never complete. Rather, challenging it was an ongoing process:

*"... stigma prevails, it still prevails now, it is not as if you wake up one day and it is gone. I think the process of getting rid of it is very gradual."*

He added that a great deal of behaviour change occurred because HIV/AIDS was kept on the agenda continually:

*"I don't think one just learns about stigma, and the development then involves the immediate change of attitude. I don't think this happens so much because of circulating an expert document either. It happens more because of the fact that it is kept on the agenda, and it is then always discussed."*

### *4.1.3 Lessons learned*

Mr Knigge highlighted a number of crucial lessons that had been learned in the experience of the IDC:

- keep HIV/AIDS on the agenda continuously
- use every informal opportunity to network with other departments or organisations
- learn from other departments and organisations, and don't reinvent the wheel
- challenge gender messages since they also contribute to stigma
- changing attitudes about HIV/AIDS takes time – don't expect quick results
- employing people who are openly HIV positive provides a strong message of acceptance in the workplace with a ripple effect.

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<sup>3</sup> <http://www.undp.org.za/projects/gipa.html> <http://www.unaids.org/publications/documents/persons/JC-IPA-ii-E.pdf>



## 4.2 Providing technical support for a HIV/AIDS-friendly public service

### 4.2.1 Background

In 2000 the Minister of Public Service and Administration, Ms Geraldine Fraser-Moleketi, initiated the Impact and Action Project on HIV/AIDS. The aim of the project is to ensure that the Public Service will be able to maintain a quality service in spite of the progression of the AIDS pandemic. The project was set up in three phases. The first phase, an impact assessment aimed at establishing the magnitude of the pandemic and its impact on the public service. The second phase entailed the development of an appropriate legal and policy framework and a comprehensive plan of action to mitigate the impact of HIV/AIDS (including HIV/AIDS stigma). The last phase is the ongoing implementation of policies and systems, which were developed, in the second phase.

According to Ms Ndivhuwo Chauke, a specialist in the Department of Public Service and Administration (DPSA), who was interviewed regarding the stigma-mitigation aspects of the Impact and Action Project, it had had a far-reaching impact on a range of government workplaces.

### 4.2.2 Activities to reduce stigma

#### **Conducting an impact assessment study**

The first phase was the impact assessment study in November 2000, which provided an overview of the multiplicity of effects of the HIV/AIDS pandemic on the government workplace – impacting not only on government employees in terms of infection, but also in terms of constraining service provision and delivery. The impact assessment gave the project team a clearer perspective on where and how they needed to act to mitigate the effects of HIV/AIDS, in order to best sustain service delivery.

#### **Developing a policy framework**

In the second phase of the project, a public service policy framework was developed to guide government departments on minimum standards for the effective management of HIV/AIDS in the workplace.

As Ms Chauke commented:

*"We had to go back and review all the policies and legislation in the public service ... to basically come up with principles for managing HIV/AIDS in the workplace. And we also had to look at our legal framework to check if it contradicts any of the key principles in managing HIV/AIDS in the public service."*

She said that the DPSA had then been faced with two options: to develop a one-size-fits-all type of policy for all departments, or to create a framework, which stipulated minimum standards and allowed government departments to develop sector-specific policies. The second option had been chosen, in order to allow for greater flexibility in policy development.

The minimum standard had, however, stipulated that:

*"The heads of departments must ensure that none of the policies and [human resources] practices discriminate against people who are living with HIV/AIDS. And heads of department must take reasonable steps to ensure that discrimination doesn't take place."*





### **Amending public service regulations**

The framework resulted in the amendment of the Public Service Regulations, 2001 to provide for effective management of HIV/AIDS in the Public Service. In addition, the DPSA developed a workplace manual entitled *Managing HIV/AIDS in the Workplace: A Guide for Government Departments*<sup>3</sup>, to provide practical advice and information on how best departments could respond to the pandemic. This included addressing stigma in the workplace.

### **Improving employee benefits**

The Public Sector had gone further to improve employee benefits so as to assist staff members who were infected or affected by HIV/AIDS. The benefits included improved funeral benefits, pensions for orphans, the restructuring of pensions for spouses, and an extension of the previously narrow definition of spouse for government employees.

The process of restructuring of health benefits were still not complete at the time of interviewing, but Ms Chauke commented that it was hoped that all public servants would eventually be covered by some form of medical insurance. The provision of health benefits would send a strong message about acceptance of PLHAs in the public service, and hence reduce stigma.

### **Getting departments to commit**

Ms Chauke said that the DPSA was proud that national government departments had been highly committed to developing HIV/AIDS workplace policies, and that almost all now had such policies in place. Provincial departments are coming on board as well

She commented that dealing with HIV/AIDS stigma through workplace policy was challenging. Normal grievance procedures can be followed for employees to redress if they felt they were being treated unfairly because of their HIV status.

### **Organising an annual AIDS indaba**

An ongoing contribution of the Impact and Action Project had been to organise an annual Public Service AIDS Indaba for national and provincial government departments. The Indabas serve as a learning session for government departments to explore workplace strategies in preventing and managing the spread of HIV/AIDS. The first indaba was held in 2001, and this meeting had played a critical role in shaping the policy framework for the Public Service. The second AIDS Indaba held in 2002 provided for capacity development to ensure proper implementation of the minimum requirements as stated in the Public Service Regulations. It had also served as a valuable forum to reduce HIV/AIDS stigma in government workplaces by encouraging management representatives, which attended the indaba to talk openly about their departments' HIV/AIDS issues. It enabled departments to discuss problems and to share solutions.

In 2003, this forum was also used to share the results of HIV/AIDS stigma research project that was conducted in national departments by the *Siyam'kela* Project – this was a monitoring process for the public service.

### **Shifting to implementation**

Ms Chauke said that the third phase of the Impact and Action Project, had begun in 2003. In this phase the focus was to shift to implementation of policies and systems, which were developed in the second phase. DPSA is providing support to Government departments as they develop and implement their own HIV/AIDS policies and programmes.

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<sup>3</sup> Department of Public Service and Administration, (2002). *Managing HIV/AIDS in the Workplace: A Guide for Government Departments*. Access at <http://www.dpsa.gov.za>



### 4.2.3 Lessons learned

According to Ms Chauke, a number of important lessons had been learned from the DPSA's experience of providing technical support:

- a thorough impact assessment provides the foundation for all effective HIV/AIDS-related interventions
- a minimum standard framework allows different departments to be more flexible and to develop unique strategies to deal with the HIV/AIDS pandemic
- by improving employee benefits organisations can ensure that PLHAs are healthy and able to contribute in the workplace as long as possible. This measure also reduces stigma
- the annual AIDS indaba provides an important mechanism for departments to share information and to jointly develop useful strategies about HIV/AIDS policy and stigma reduction.

## 4.3 Appointing someone living with HIV/AIDS in the workplace

### 4.3.1 Background

The United Nations Development Programme (UNDP) has for some time called for implementation of the Greater Involvement of People Living with HIV/AIDS (GIPA) principle in the workplace. The UNDP declares that:

*"People living with and affected by HIV/AIDS should share the lead and responsibility in responding to the epidemic, while encouraging society to create a space for them to play this role ... no community, government or institution can alleviate the impact of HIV/AIDS without embracing those infected or affected."*

### 4.3.2 Activities to reduce stigma

#### Lobbying for the GIPA principle

The EAP professional at Statistics South Africa (STATS SA), a National Government Department, Ms Keneilwe Theo, was interviewed regarding her experience of implementing the GIPA principle in that organisation. She said that she had been appointed to STATS SA in March 2002 to run EAP, including the HIV/AIDS Programme. Ms Theo mentioned that she became concerned:

*"About those employees who are HIV positive but are not disclosing, and I wanted to educate them about how to take care of themselves ... We used to invite someone openly living with HIV/AIDS from outside to give a presentation or talk ... Then in late 2002, I spoke to my director and requested her to consider employing someone living with HIV/AIDS who was open, along the GIPA principle."*

Ms Theo explained that what had motivated her was that the Department of Health had recently begun a project to employ PLHAs within workplaces, and it had started seeing real benefits from doing this. This principle of GIPA was not new to the departments hence she had to lobby her senior management for this position to be considered:

*"... initially, management was skeptical about this appointment, and I had to take them through the GIPA model, how it works, what had been the success in other organisations like at Eskom, and the South African Police Services (SAPS). I took my director with me to the SAPS [to look at their HIV/AIDS policies]. Then we finally got management buy-in."*



### **Marketing the successes of the GIPA model**

At STATS SA a wide range of benefits had accrued from the employment of a PLHA in terms of the GIPA model, Ms Theo commented. She stated that some employees had subsequently disclosed their HIV-positive status in the workplace, and had approached the EAP programme for assistance. There had been extensive benefits in terms of destigmatisation of HIV/AIDS in the workplace, far beyond what had been made possible by educational programmes.

Ms Theo also pointed out the positive outcomes in terms of providing a positive role model for other PLHAs. A visible PLHA provided a clear demonstration that the workplace was supportive of PLHAs. The role model of the visible PLHA served to destigmatise the disease by disproving HIV/AIDS stereotypes of vulnerability and weakness. In addition, such a PLHA had unique experience and expertise that could serve to inform the development of workplace programmes. By involving a PLHA, workplace programmes would have greater credibility and be more likely to reflect the concerns of employees living with HIV. A visible PLHA could finally be a spokesperson for stigma mitigation.

### **Expanding the GIPA process**

The success of the GIPA model in the government workplace is shown by the fact that currently at least ten government departments employ a PLHA in their HIV/AIDS programmes.

### **Implementing the model with care**

Ms Theo suggested that the GIPA model needed to be implemented sensitively. She argued that apart from his or her HIV status, the PLHA employed in such a position needed to have other skills and aptitudes relevant to the workplace. Where the appointment of a GIPA person had failed, she said, often the person employed had not had relevant work and project-related skills. A clearly defined job description should also be in place and the appointment should be in accordance with job requirements.

Other interviewees have cautioned that a careful and thorough process needs to be followed in order to find a PLHA who is suitable to assume a GIPA role in the workplace. Such a person should have been comfortable with their HIV status for some time, and should have learned to confront their own internalised stigma. In addition, they need to have had extensive experience of having disclosed their status to others, and having had to deal with a range of responses, including negative ones.

Another comment, which has been made, is that a PLHA who has disclosed should have disclosed their status for appropriate reasons e.g. because they are comfortable with their status, not because they will obtain financial gain from disclosure. Finally, a person who is appointed in terms of GIPA principles will be highly visible and exposed in the organisation, and so very vulnerable. Such a person needs to have a high degree of emotional resilience to cope with the demands of the GIPA role.

Nevertheless, the broad range of benefits, which accrue from application of the GIPA principle in the government workplace suggest that it is a powerful tool in reducing HIV/AIDS stigma.

#### *4.3.3 Lessons learned*

A number of important lessons were mentioned in the course of interviews regarding the GIPA principle:

- it is important that top management is brought on board in order for the employment of a visible and disclosing PLHA to be successful
- the success of the principle depends to a large extent on the calibre of the person employed





- a person employed in terms of GIPA needs to have skills and abilities relevant to the workplace, apart from their HIV status
- the person employed needs the ongoing support of management in order to be effective.

## 4.4 Developing a progressive workplace programme

### 4.4.1 Background

The HIV/AIDS Workplace Programme of the South African Police Services (SAPS) was chosen for this study of promising practice in terms of stigma mitigation because of a range of features which it possesses, and which are seen as uniquely progressive.

The SAPS Workplace Programme was started in 1996, which means that it predates the minimum standards framework for HIV/AIDS policy developed by the Department of Public Service and Administration. It drew many lessons from the Department of Defence's experience of dealing with HIV/AIDS in the workplace during the 1980s and 1990s.

The programme covers both police employed in terms of the South African Police Act and civilian staff. In the 2004/2005 financial year R10 million was allocated to the SAPS Workplace Programme for HIV/AIDS.

### 4.4.2 Activities to reduce stigma

#### Getting support at all levels

The SAPS HIV/AIDS Workplace Programme is managed countrywide from a national office. The programme enjoys the full support of the minister of safety and security, Mr Charles Nqakula, the national commissioner, Mr J S Selebi, and provincial and divisional commissioners countrywide. Their support for the programme is seen as a key factor in its success.

#### Providing education and awareness

The workplace programme began with an HIV/AIDS education and awareness programme developed in accordance with the policy of the Department of Defence. The programme was conceptualised in terms of a cascading programme of information, strategically targeting staff at all levels. It comprises of :

- the distribution of condoms through condom dispensers in all police stations throughout South Africa
- the provision of support groups for employees who are HIV positive; the support groups are run by professional social workers
- 23 master trainers who were trained nationally by the Department of Defence
- 250 social workers who were given training to become HIV/AIDS educational officers
- between 1 800 and 2 000 peer educators who were trained in all aspects of HIV/AIDS.

Each peer educator is assigned to target a specific number of staff members. The eventual goal is a ratio of 50 staff members to one peer educator.

#### Treating medical conditions

Treatment for HIV/AIDS-related conditions for police was provided through the disease management programme of Polmed, the SAPS medical aid scheme. Civilian employees were generally covered by other medical aid insurance. Availability of treatment is believed to have an impact on the increasing use of VCT facilities by staff members.



### **Promoting testing in the workplace**

SAPS has launched voluntary counselling and testing in all provinces. During these launches, the benefits of testing are highlighted through the marketing of different workplace programmes. The minister and the commissioners also publicly tested for HIV, contributing to the destigmatisation of HIV testing. The message is “know your status and then you can manage it”

### **Offering continuity of care and support in the workplace**

SAPS runs a support centre that is staffed by social workers, psychologists and chaplains. A 24-hour stand-by phone line is run by social workers for counselling and referrals provincially.

### **Managing diversity**

SAPS also runs proactive programmes for staff development, including a series of workshops on diversity and building of coping and life skills in the workplace.

### **Building partnerships**

Partnership is seen as an integral part of the workplace programme. It involves extensive collaboration with the Department of Defence and the IDC.

#### *4.4.3 Lessons learned*

In the course of developing the HIV/AIDS Workplace Programme of the South African Police Services, a number of important lessons were learned:

- HIV/AIDS policies and programmes do not always need to be developed afresh. It is possible to learn valuable lessons from other organisations' experiences
- it is crucial to a programme's success to have the commitment of all levels of management
- a cascading programme of information provision strategically targeting employees at different levels can be very effective
- peer educators can play an important role in raising awareness.

### *4.5 Key findings*

A number of most promising practices emerged from the interviews with representatives of the government workplace. Whilst to a certain extent different dynamics drive the government and the private sector. It is believed that there are common principles with respect to HIV and AIDS workplace programmes. Thus lessons learnt and principles obtained from the public sector experience with stigma reduction have wider applicability to other formal sector workplaces. The most important of these most promising practices were the following:

- conducting an impact assessment study, in order to provide an idea of how the HIV/AIDS pandemic will impact on government departments
- conducting a comprehensive HIV/AIDS policy analysis by all government departments, focusing specifically on how departments are addressing HIV/AIDS, including stigma issues. The analysis also needs to assess whether or not policies in place reinforce HIV/AIDS-related stigma
- the implementation of the Greater Involvement of People Living with HIV/AIDS (GIPA) model. The visibility and openness of PLHAs will demonstrate that the workplace environment is supportive of PLHAs, as well as provide positive role models to other PLHA employees, and so serve to destigmatise the disease



- procuring the wholehearted commitment of senior management to a workplace HIV/AIDS programme. The experience of the South African Police Services Workplace Programme has shown that this is vital to a programme's successful implementation
- integrating messages challenging HIV/AIDS stigma into ongoing communications in the workplace, in order to have a pervasive effect on group culture
- challenging attitudes to HIV/AIDS through horizontal rather than vertical interventions
- using networking across departments to share HIV/AIDS expertise effectively
- providing support groups for PLHA employees, run by professionally trained facilitators
- providing sufficient numbers of well trained HIV/AIDS peer educators, equipped with sufficient knowledge of basic facts and the appropriate interpersonal skills to pass on their knowledge to employees
- improving employee benefits, especially for health care, pensions and orphans
- monitoring all HIV/AIDS interventions to ensure their sensitivity to stigma; it is crucial that interventions do not unwittingly increase stigmatisation.

## 5. *PLHAs who interact with the media*

The final section of this document focuses on the documentation of promising practices to mitigate HIV/AIDS stigma, with a particular focus on PLHAs who interact with the media.

All participants were asked to reflect on their experience of working with the media, and to derive useful principles from this experience, which could be helpful to other PLHAs involved in interacting with the media.

All the PLHAs who were interviewed for this part of the study emphasised the importance of dealing with personal disclosure issues prior to interacting with the media. They said that it was crucial to have disclosed one's HIV-positive status to relatives, friends and work colleagues before talking about one's status to the media. They also mentioned that the process of having addressed internalised stigma was empowering of any PLHA who wanted to interact with the media.

A counsellor at a voluntary counselling and testing (VCT) centre in Soweto, Ms Tiro, and a TV presenter, Mr Jacobs, both suggested that it was important for a PLHA to have advance knowledge of what the media wanted in an interview, in order to be properly prepared. It was helpful, too, to request a say in the shape of the final media product.

Mr Busse, a freelance educator and trainer, said that the media tends to tell a narrow range of stories about HIV/AIDS, and that they need to be encouraged to tell more positive and more complex stories. Other PLHAs concurred with this statement in various ways. Mr Nchodu argued for the media to take note of the experiences of ordinary, working class PLHAs.

The promising practices outlined by the PLHAs who were interviewed because of their experience of interaction with the media are described in greater detail below.



## 5.1 A journey of a thousand miles (Makase Nchodu)

### 5.1.1 Background

Makase Nchodu is 34 years old and lives in Soweto. He was a member of Umkhonto we Sizwe, the military wing of the African National Congress (ANC) in exile, prior to the unbanning of the organisation in 1994. Mr Nchodu served as head of publicity of the ANC in Uganda. After returning from exile he served in the integrated South African National Defence Force. It was there that he tested HIV positive in 1995. Mr Nchodu currently works as a programme officer for the AIDS Care Counselling and Training Programme (ACCT) at Baragwanath Hospital in Soweto, where he also runs a support group for males living with HIV/AIDs. He is also involved in the Jozi FM radio programme on HIV/AIDS stigma, on which he regularly appears as a guest speaker, and has written several articles for local newspapers. A journey of the thousand miles refers to his involvement to the struggle for liberation and subsequent journey through denial, acceptance and disclosure of HIV status in the new South Africa.

### 5.1.2 Activities to reduce stigma

#### **Confronting fear of the media**

Mr Nchodu said that he thought it was very important for PLHAs to confront their own fears of working with the media:

*"You need to break the fear of PLHAs raising their issues with the media ... you need to know that it is not always a bad experience to deal with the media, it can be very rewarding too. We must not be inhibited by the fear of what can go wrong."*

He pointed out that confronting fear of the media also involved dealing with one's own internalised stigma as a PLHA. All PLHAs are affected by the stigmatisation of the larger community, and before one could be effective in media work one had to confront one's own internalised stigma which could be very immobilising.

#### **Thinking carefully about disclosure**

Mr Nchodu said that the decision to disclose publicly in the media needed to be considered very carefully, and the possible consequences assessed:

*"The consequences are different for a middle-class person compared to say, a woman who is living in an informal settlement, and who is unemployed and dependent on her husband or boyfriend for support. What happens to the woman when her male partner chases her out of the home?"*

#### **Acknowledging media realities**

According to Mr Nchodu, one needed to be realistic in working with the media and recognise that it had a long history of not producing useful or empowering images of PLHAs:

*"The media has at times not been helpful in fighting stigma. At one point maybe 40% [of media practitioners] are fighting stigma, but 60% are increasing stigma."*

In practice, this meant that as a PLHA, one needed to be critical of media reporting and willing to challenge the media wherever necessary.

#### **Getting training**

Training was described by Mr Nchodu as vitally important for any PLHA who wanted to work effectively with the media:



*"When dealing with the media one needs training. You need to learn how to be vocal ... You need to be prepared, know exactly what you are going to say, because if you are not prepared at times you end up dealing with emotional issues rather than dealing with the real issues at hand."*

### **Preparing for interacting with the media**

Mr Nchodu said that good interviews with PLHAs inevitably arose out of having prepared well for the event:

*"Prior preparations prevent poor presentation."*

This included checking up on any factual information one was likely to be asked about, making oneself aware of the focus of the media interview, and deciding clearly beforehand how much of one's personal story one was prepared to tell.

### **Including the voices of ordinary people**

According to Mr Nchodu, the media tended to interview a small group of articulate and accessible PLHAs:

*"... In the field of AIDS at the level of media there are very few people and those people are outspoken, and they have become the spokespersons for everyone who has HIV/AIDS. There has never been a chance for ordinary people to speak out. That is the problem with the media, they want famous people. In most cases ordinary people who are living with HIV/AIDS do not get interviewed."*

He argued strongly that it was vitally important for the media to take note of more ordinary, working class people. Ordinary PLHAs needed to be actively sought out and their views reflected by the media:

*"The feeling among ordinary people living with HIV/AIDS is that they also need to be included as part of the leadership in talking to the media."*

### **Providing a counterbalance to negative stories**

Mr Nchodu contended that the media had tended to provide stigmatising perspectives on those living with HIV, and that this needed to be counterbalanced by more encouraging accounts:

*"The more positive things we talk about as people living with HIV/AIDS, the more the media can reflect this and people can see there is life after becoming positive."*

### **Having a say in the final product**

Mr Nchodu felt that it was useful as a PLHA who was interviewed to be able to see a draft of the final product before it was broadcast or published, in order to correct any misconceptions. It was also important to do this in order to fill in inadvertent gaps or omissions, and to point out stigmatising language.

#### *5.1.3 Lessons learned*

According to Mr Nchodu, a number of important lessons could be learned from his experiences with the media:

- personal, internalised stigma needed to be tackled first
- good preparation makes for a better outcome
- sound training equipped PLHAs better to cope with the media
- the stories of a wide range of PLHAs from all backgrounds merited inclusion.



## 5.2 Embarking on the journey of disclosure (Vuyani Jacobs)

### 5.2.1 Background

Vuyani Jacobs lives in Cape Town. He is involved in the Treatment Action Campaign (TAC) in the Western Cape. He co-produces and also appears as a presenter on *Beat It*, a weekly programme on the etv television channel, which addresses the lives and challenges of PLHAs. Mr Jacobs has extensive experience of working with the media, including print and radio.

### 5.2.2 Activities to reduce stigma

#### Dealing with personal disclosure issues

Mr Jacobs said that in his experience, it was crucial for a PLHA to deal with his or her own personal disclosure issues before talking to the media:

*"It's important to deal with disclosure to family and friends and colleagues before you start disclosing publicly in the media. You shouldn't wait until they learn about your status through a TV programme."*

By dealing with personal disclosure first, one could make sure that personal issues would not cloud the interaction with the media and would feel able to talk more freely without being inhibited by fears of who might see the finished media product.

#### Dealing with internalised stigma

Mr Jacobs believed that PLHAs needed to confront and challenge their own internalised stigma, in order to work effectively with the media:

*"Stigma comes in a large part from within ourselves, [and affects] how we deal with issues."*

#### Making stigma visible

Mr Jacobs believed that it was helpful for media programmes to focus directly on stigma:

*"Stigma is part of the everyday focus of Beat It, because it talks about HIV everyday, it puts stigma in front of everyone, it says, don't ignore me."*

By making the issue of stigma explicit, the public were compelled to think about how they themselves engaged in stigmatisation. In this way, HIV/AIDS stigma is challenged and therefore could be reduced.

#### Preparing for an interview

A PLHA needs to get as much information as possible in advance from the media practitioner, in order to be able to prepare effectively:

*"You don't need to know all the questions. But it's good to know in advance what you are going to talk about, to prepare."*

#### Providing context

Mr Jacobs believed that the media sometimes had a tendency to report statements made by PLHAs out of context, which could lead to major misunderstandings and further stigmatisation. He felt that it was important for PLHAs to always insist that their comments be given a clear social context. One way of exercising control over this issue was for PLHAs to be provided with a draft of the final media product before it was disseminated.





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### Focusing on personal growth

Mr Jacobs said that discussion of PLHAs and the media tended to focus on the PLHAs' ability to influence the media. However, there was also the possibility of influence in the opposite direction:

*"... using the media as an institutional process also means the growth of a person. The more you can interact in the best way, the more you can grow as a better person in yourself."*

### Sharing expertise

As PLHAs acquired experience in working with the media, Mr Jacobs said, that expertise could be shared and the overall level of community expertise improved:

*"The skills [that a PLHA has] in working with media can be taught and transferred. It's important to build up other people ... to transfer leadership in working with media."*

#### 5.2.3 Lessons learned

Mr Jacobs said that a number of important lessons could be learned from his experiences with the media:

- personal disclosure issues needed to be managed before working with the media
- PLHAs should prepare in advance for interacting with the media by asking questions of the media practitioner
- interacting with the media could enhance personal growth
- PLHAs' media expertise should be shared and passed on.

### 5.3 Defying stigma (Pinky Mabuza Tiro)

#### 5.3.1 Background

Ms Pinky Mabuza Tiro is a 54-year-old married woman living in Soweto, Johannesburg. She has three children and five grandchildren. She said that her first experience of stigma dated back to her schooldays, when she was stigmatised for being born the daughter of a Shangaan (a historically marginalized group, which was often associated with backwardness in South Africa) father and a coloured mother. Ms Tiro has known for more than ten years that she is HIV positive. She has appeared in two television documentaries, *Positive Living* and *Steps for the Future: A Red Ribbon around my House*. She also does radio talks on regular basis for community radio stations in Soweto and has featured in numerous local newspapers as a PLHA. Ms Tiro is passionate about caring for and supporting people infected with and affected by HIV/AIDS. She currently works as a counsellor at a voluntary counselling and testing (VCT) centre at the Mandela-Sisulu Clinic in Soweto. Ms Tiro is also involved in home-based care, runs a beadwork training programme for PLHAs, and has a concern for children orphaned by HIV/AIDS.

#### 5.3.2 Activities to reduce stigma

##### Dealing with personal disclosure first

Ms Tiro felt that it was crucial for a PLHA to talk to their family members, friends, neighbours and work colleagues first about disclosure:

*"... family disclosure comes first. You have to tell them before you tell anyone else. Then tackle the people around you, and the colleagues."*



She cautioned that anyone who had recently been informed of their HIV- positive status needed time to come to terms with the diagnosis. One needed to have built up a strong degree of personal resilience before dealing with the media:

*"... if recently diagnosed, it's important to come to terms with the disease first before doing any talking to the media. Avoid them at this early stage. Don't talk to the media until you are ready."*

### **Being aware of the power of the media**

Ms Tiro said that in her view the media had enormous power to affect people's perceptions, and especially their self-perceptions:

*"The media can build you up and they can break you. So you must treat them with lots of caution. You can't talk without thinking very, very carefully first about what to say."*

She elaborated further:

*"As people living with HIV/AIDS we all have our own personal journeys, our own personal stories. It's a journey of which in many cases the media might want an expert opinion. Handling the media is about dealing with our own personal experiences."*

### **Establishing a personal support base**

Ms Tiro was of the opinion that a PLHA needed to have strong support from those close to them (including family members and friends) in order to cope well with the media:

*"Make sure the family members know what you are going to do [i.e. interact with the media]. Don't just go it alone. They must understand, because if there is negative reaction, they will also be affected."*

A good support system enabled a PLHA working with the media to develop emotional resilience and to cope better with less than favourable reactions from members of the public.

### **Preparing beforehand**

Ms Tiro said that it was important that if a PLHA was interviewed for radio or television they were able to enquire beforehand what to expect. This included details regarding the exact topic for the show, and what questions they were likely to be asked. It was not reasonable, in her view, for media practitioners to expect those living with HIV/AIDS to make themselves available without being fully informed of the nature of the media interaction.

### **Knowing what you want to say**

Ms Tiro suggested that one should not feel passive in dealing with the media. Rather:

*"Know what you want to say. Don't be shy about deciding the point of view you want to put across. Say it!"*

If a PLHA was aware of what they wanted to convey, communication would be clearer and there was a greater chance that they could influence the media message positively.

### **Challenging use of language**

Media practitioners, Ms Tiro said, were often careless about the language they used to talk about PLHAs. They used language, which was offensive, hurtful and stigmatising. She said that PLHAs who interacted with the media should take a firm stand about what language was acceptable and what was not. They should also challenge media stereotypes:

*"I have said we should tell them that PWA does not stand for person with AIDS, but instead for person with ambition. I mean we also have hopes and dreams too."*





### 5.3.3 Lessons learned

According to Ms Tiro, a number of important lessons could be learned from her experiences with the media:

- talking to family first before talking to the media
- the media had enormous power – don't underestimate it
- knowing what you wanted to say would make your communication to the media clearer
- challenging the media's use of language.

## 5.4 Challenging attitudes through the media (Peter Busse)

### 5.4.1 Background

Mr Peter Busse is 46 years old and lives in Johannesburg. He was diagnosed HIV positive in 1983 while living in Swaziland. Mr Busse returned to South Africa in 1987 and began work in the HIV/AIDS field. He initially worked as a counsellor at the Hillbrow Community AIDS Centre, and underwent the first volunteer counselling training course at the South African Institute for Medical Research. He was one of the founders of the Township AIDS Project and has also worked for NAPWA. Mr Busse later became involved in HIV/AIDS training, and currently works as a freelance trainer and educator.

Peter Busse has been involved in a wide range of media activities. He has conducted training with PLHAs, raising awareness on how the media shapes societal fears of HIV/AIDS and discussing ways to address this; trained journalists on the portrayal of people living with HIV/AIDS, an initiative of the Institute for the Advancement of Journalism; provided technical support to two PLHA presenters and producers of the TV series *Positive*, including giving input to radio stations and print media; and appeared in *Living Openly*, a collection of case studies of PLHAs by the Department of Health, with photographs by Gisele Wulfsohn.

### 5.4.2 Activities to reduce stigma

#### Seeing disclosure as a personal process

Regarding disclosure, Mr Busse said that:

*"Disclosure is a finely nuanced process which is different for every person ... I think it is important for the media to be aware of how far a PLHA has gone with disclosure, and to know then how much they can say about the person. Disclosure also has a political dimension. Some people in South Africa have disclosed to enhance visibility of the disease hence facilitate political decision-making regarding HIV/AIDS."*

#### Getting prior access to questions

According to Mr Busse, to a large extent good preparation for a media interview depended on getting access to questions and scripts beforehand. It was reasonable to expect media practitioners to provide a list of questions in advance, so that a PLHA could prepare well.

#### Challenging language used by the media

Mr Busse said that the media had been unhelpful in the past to change the language they used to describe people who were living with HIV/AIDS, but that this had changed. It was vital for PLHAs to continue to challenge stigmatising phrases and words:

*"it's important to challenge the language used, particularly words like 'victim'. You know the voices of PLHAs have been heard by the media, like: 'We don't want to just be seen as people with AIDS, we want the living component added, so it's people living with HIV/AIDS.'"*



### Encouraging media to tell a range of stories

The South African media, in Mr Busse's view, had related a narrow range of stories about PLHAs. In doing so, they had failed to do justice to the complexity of experience of different PLHAs from a wide range of backgrounds, including race, gender, class, language group, geographic area and sexual orientation:

*"Often stories have focused on the obvious. They have been driven by the mainstream take. We need different stories in the media, about all the different kinds of experiences."*

### Telling positive and more complex stories

Mr Busse said that the media also needed encouragement to not just tell stories about HIV diagnosis or current HIV/AIDS political issues, but also:

*"... tell stories about the complex process of living with HIV. More is now being shown on film. But other media are still putting out the same old messages. We need to get the media to talk about what it is like. We have had some people now living with HIV for more than 20 years."*

Finally, Mr Busse said, stories could be 'complexified'. This meant telling more interesting stories about the full complexity – good and bad – of living with HIV/AIDS in South Africa in 2004. In this way the media could help to challenge old stereotypes and destigmatise the disease.

### 5.4.3 Lessons learned

Mr Busse said that a number of important lessons could be learned from his experiences of the media:

- making the media aware of how much of what the PLHA says can be disclosed
- taking charge of the media experience, and disclosing when the PLHA feels this is right
- challenging the language used by the media
- encouraging the media to reflect the full range of South African HIV/AIDS stories
- encouraging the media to tell about the complex process of living with HIV/AIDS over time.

### 5.5 Key finding

A number of promising practices emerged from the interviews with PLHAs who had had experience of interacting with the media. The most important of these most promising practices were the following:

- dealing with personal disclosure issues first before talking to the media. All the PLHAs interviewed identified it as of crucial importance to personally disclose one's HIV status to family members, colleagues and friends before disclosing through the media
- confronting personal internalised stigma before interacting with the media
- obtaining as much information as possible from the media practitioner in advance, in order to prepare well for the media interaction
- establishing a personal support base for oneself in order to deal effectively with the media
- being proactive rather than reactive, and deciding on clear messages to communicate through the media
- challenging stigmatising language used by the media
- encouraging the media to tell a range of stories reflecting the complexity and range of PLHAs' lives, including the lives of ordinary people



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- encouraging the media to tell more positive stories
- asking the media to see a draft of the final product before broadcasting or publishing, in order to be able to correct errors and misconceptions
- sharing between PLHAs the expertise already gained in interacting with the media.
- providing PLHAs with skills to work with the media.

## 6. Conclusion

This report has outlined promising practices for HIV/AIDS stigma mitigation in three areas: faith-based organisations, the government workplace, and PLHAs who interact with the media. It is clear from the findings that different contexts require a range of differing responses.

The interviews nevertheless make it clear that in each of the contexts, which were examined, it is possible to employ a variety of strategies to reduce stigma. It is hoped that the promising practices, which have been described, may be useful to others working in these three areas and concerned about stigma mitigation.

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